

MRDR Sites

Adelaide Cancer Centre: Anthony Cheung
 Alfred Hospital: Andrew Spencer
 Austin Hospital: Simon He
Bairnsdale Regional Health Service: Amanda Ormerod
 Bendigo Hospital: Robert Blum
 Box Hill Hospital: Jay Hocking
 Cabrini Hospital: Gaurav Srivastava
 Canberra Hospital: James D'Rozario
 Christchurch Hospital: Ruth Spearing
 Concord Hospital: Jane Estell
Dunedin Hospital: Ian Morison
 Epworth Freemasons Hospital: Miles Prince
 Flinders Medical Centre: Magdalena Sobieraj-Teague
 Frankston Hospital: Patricia Walker
Geelong Hospital: Philip Campbell
 Hollywood Private Hospital: Bradley Augustson
 ICON Cancer Care: Kerry Taylor
 - South Brisbane
 - Wesley
 - Cherside
 - Southport
Jarrett St Specialist Centre, Gosford: Cecily Forsyth
 Latrobe Regional Hospital: Tricia Wright
 Lismore Hospital: Louise Imlay
 Liverpool Hospital: Sylvia Ling
 Middlemore Hospital: Hilary Blacklock
 Monash Medical Centre: George Grigoriadis
 Nelson Hospital: Luke Merriman
 Northern Hospital: Teresa Leung
Northland Hospital: Sarah Poplar
 Peter Mac / Royal Melbourne: Michael Dickinson
 Princess Alexandra Hospital: Peter Mollee
Central Gippsland Health Service: Amanda Ormerod
 Sir Charles Gairdner Hospital: Bradley Augustson
 St George Hospital: Sundra Ramanathan
 St Vincent's Hospital, Melbourne: Hang Quach
 St Vincent's Hospital, Sydney: Nada Hamad
 Sunshine Hospital: William Renwick
Sunshine Coast University Hospital: Anthony Powell
 Royal Brisbane and Women's Hospital: Jason Butler
 Royal Darwin Hospital: Akash Kalra
 Royal Hobart Hospital: Anna Thompson
 Royal North Shore Hospital: Ian Kerridge
 Royal Prince Alfred Hospital: P Joy Ho
 Wellington Hospital: Anup George
(Italics = governance approval pending)

MRDR Team Members

Coordinating principal investigator: Prof Andrew Spencer - The Alfred Hospital & Monash University
Administration: Transfusion Research Unit (TRU), Monash University
Head of TRU: A/Prof Erica Wood
Associate investigator: Dr Zoe McQuilten
Research Fellow/Project Manager: Dr Liz Moore
Data Manager: Dr Cameron Wellard
PhD student / Haematologist: Dr Krystal Bergin
Senior Projects Officer: Mr Neil Waters
Research Officer: Ms Laura Sellick
Project Officer (AMARC): Ms Samantha Francis-Pester

AMARC Clinical Trials (see page 2)

KappaMab: A Phase IIb, open label, sequential cohort study comparing KappaMab alone to KappaMab in combination with lenalidomide and low dose dexamethasone (MRd) in Relapsed Refractory Multiple Myeloma. 19 patients enrolled

ITD: A prospective, multi-centre, single arm, phase 2 assessment of the efficacy and safety of the combination of ixazomib, thalidomide and dexamethasone (ITD) for relapsed and/or refractory multiple myeloma after 1 to 3 prior lines of therapy. 29 patients enrolled

VCDD: A randomized phase 2 study of bortezomib, cyclophosphamide and dexamethasone induction (VCD) compared with VCD and daratumumab induction followed by daratumumab maintenance (VCDD) for the initial treatment of transplant ineligible patients with MM. 18 patients randomised

Welcome to the MRDR annual report! 2017 marked a year of significant growth for the registry and we expect a very positive and productive 2018.

MRDR activities

Participation: Recruitment reached more than 1800, with 1245 multiple myeloma (MM) and 516 monoclonal gammopathy of undetermined significance (MGUS) patients recruited from 27 hospital sites. Fourteen new sites have approval pending. The MRDR is also becoming more representative of regional hospitals and the private sector.

Data Linkage: Our first linkage with the Australian National Death Index (NDI) was performed in 2017. Mortality is a key outcome with potential for loss to follow-up, and linking with the NDI ensures its accuracy. Linkage with the Victorian Cancer Registry was also conducted and we are in the process of assessing MRDR case capture for MM in Victoria. These are key data quality measures supporting the MRDR.

Publications are listed at the end of this report, with more in the pipeline on renal impairment and stem cell transplantation in MM.

Presentations at key state (1), national (6) and international (3) meetings were made in 2017 on diagnostics and treatment, renal impairment, stem cell transplant, outcomes for people of Pacific Islander ethnicity, and patient-reported outcomes (see page 2).

Substudies

The Myeloma 1000 project reached 204 patients enrolled (95 MM: 109 MGUS) and is the only prospective fully annotated 'liquid biopsy' biobank in the world. This study leverages the MRDR database to link biological data with clinical data to better predict treatment response and identify patients at risk of developing MM or disease progression. It



Blood is taken at sites, sent to the Alfred Hospital campus, processed then freeze-stored

involves recruitment of 1000 MM and 1000 MGUS patients pre-treatment. There is a once-only blood collection after consent and sites receive a \$150 per patient payment. We are expanding site participation.

IMPROVE (Immunoglobulins in myeloma patients: research into outcomes, variation in practice and epidemiology) is a registry-based study recently funded by the National Blood Authority through to 2020. It will describe the use of immunoglobulins in MM, including variation in practice. The results from this study will inform policy and clinical practice related to immunoglobulin therapy in these patients.

My-PROMPT is a multicentre pilot randomised trial to test the feasibility of real-time reporting of patient-reported outcomes to clinicians treating patients with MM to



MyPROMPT study intervention

improve care. It targets newly diagnosed patients within 7 days of starting first treatment. Recruitment is underway. Takeda and Gilead fund this study.

International collaborations: There is a lot happening internationally!

Asia-Pacific expansion of the MRDR will receive funding from Janssen. Korea is the first pilot site in this process, then Singapore, Hong Kong and Taiwan. The MRDR team look forward to collaborating with regional colleagues and the opportunity to study patient characteristics, treatment and outcomes in each country.

Collaborations with sister registries in Austria (comparing diagnostics, access to care and first-line treatment) and Korea (comparing bortezomib- versus thalidomide-based first-line chemotherapy) are ongoing, led by PhD student, Dr Krystal Bergin.

International industry collaborations

- The Takeda Global Insight Registry group (USA) and Celgene Connect® MM registry group (USA) have expressed interest in collaborating with the MRDR.
- The Amgen Centre for Observational Research (USA) has requested a preliminary report of aggregate MRDR data to guide future potential collaboration.

The Australasian Myeloma Research Consortium (AMARC)



AMARC uses the MRDR as a platform for early-phase clinical trials, and recruitment to the first AMARC trials is underway (listed on page 1). The MRDR's infrastructure including data collection system and established national network of sites make it an attractive platform from which to cost-effectively conduct clinical trials.

Engaging with collaborators

The 5th annual MRDR Interest Group breakfast meeting was held in Sydney, Oct 2017 at HAA, the key haematology meeting for Australia and New Zealand. The breakfast was well attended with strong representation from sites, patient groups, and industry partners. It provided a great opportunity to showcase the registry and engage with current and new collaborators.



Priorities for the next 12 months

- Linkage with state-based cancer registries
- Data quality: Review of definitions, internal consistency checks, and outlier identification and investigation
- Formalise prospective international registry collaborations
- Ongoing targeted expansion of sites
- Enhance Myeloma 1000 Project accrual
- Increase research outputs including publications and presentations

We look forward to a dynamic and productive year in 2018. Thank you to participating sites for your hard work and enthusiasm – the MRDR depends on you for its continued progress! We also thank our funding partners for 2017: Monash Partners Advanced Health Research Translation Centre, National Blood Authority, Amgen Inc., Celgene Pty Ltd, Gilead Sciences Pty Ltd, Janssen-Cilag Pty Ltd, and Takeda Pharmaceuticals Australia Pty Ltd. We appreciate your support.

To contact the MRDR:

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Publications

- *Design and development of the Australian and New Zealand (ANZ) myeloma and related diseases registry.* Bergin K, Moore E, McQuilten Z, Wood E, Augustson B, Blacklock H, Ho J, Horvath N, King T, McNeil J, Mollie P, Quach H, Reid CM, Rosengarten B, Walker P, Spencer A. BMC Med Res Methodol. 2016 Nov 9;16(1):151.
- *Myeloma in the Real World: What Is Really Happening?* Bergin K, McQuilten Z, Moore E, Wood E, Spencer A. Clin Lymphoma Myeloma Leuk. 2017 Mar;17(3):133-144.

Presentations 2017

HAA, Sydney, Nov

- *MRDR Interest Group breakfast meeting*, A Spencer et al.
- *Renal impairment in myeloma: patient & disease characteristics, treatment, stem cell transplant & outcomes from the ANZ MRDR* (oral), J Ho et al.
- *Polynesian ethnicity and outcomes for multiple myeloma in New Zealand: a single centre study from the ANZ MRDR* (poster), H Blacklock et al.
- *Patient reported outcome measures in multiple myeloma: real-time reporting to improve care (methodology of the My-PROMPT study)* (poster), E Moore et al.

Other meetings

- *Do We Do What We Say We Should Do? Output from the Myeloma and Related Diseases Registry* (invited), K Bergin et al., Myeloma Australia Clinical Education Workshop, Melbourne, Sep.
- *Renal impairment in myeloma: patient characteristics, treatment modalities, stem cell transplant & outcomes from the ANZ MRDR* (poster), J Ho et al., European Haematology Association Congress, Jun.
- *The myeloma and related diseases registry: a tool for practice improvement* (oral), A Spencer et al., Victorian Integrated Cancer Services Conference, Melbourne, May.
- *Myeloma Australia, Medical scientific advisory group (MSAG) meeting* (invited), A Kalff et al., Melbourne, May.
- *Rates of Upfront Autologous Stem Cell Transplantation in Newly Diagnosed Multiple Myeloma* (poster), K Bergin et al., International Myeloma Workshop, New Delhi, Feb.
- *Maturing data from the ANZ Myeloma and Related Diseases Registry* (poster), E Moore et al., International Myeloma Workshop, New Delhi, Feb.